Concepts of Personhood and Mothers of Children with Disabilities

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The relationship between disability and cultural concepts of personhood have been at the heart of many cross-cultural analyses in disability studies. In this paper I raise the question of the impact evaluations of personhood have, not on people with disabilities themselves, but on non-disabled women who give birth to and raise children with disabilities. Whyte and Ingstad have claimed that "if personhood is seen as being not simply human, but human in a way that is valued and meaningful, then individuals can be persons to a greater or lesser extent (1995:11)." Since disability is often interpreted as diminishing personhood in American society, for American mothers of young children with disabilities is motherhood also diminished? How is motherhood interpreted and/or reconstructed by women who nurture children with disabilities?

An examination of the current cultural context of reproduction is crucial for answering such questions. There has been a growing literature in the fields of anthropology, sociology, and women's studies examining the part played by new reproductive technologies in transforming women's experience of pregnancy (see Rapp 1987, 1988, 1990, 1993; Layne 1990, 1992; Martin 1987; Petchesky 1987; Rothman 1986; Strathern 1992; Press, Brown and LeMaster 1993). Similarly, genetic counselors and medical ethicist have considered how prenatal testing and the predicted expansion of genetics knowledge obtained through the Human Genome Project has or will affect decisions regarding conception and/or abortion (Bosk 1992; Glover 1989; Bartels, LeRoy, Caplan 1993).

With changing gender roles and the availability of birth control and legal abortions, motherhood in general has moved from an ascribed to an achieved status in American culture (Ginsburg 1989); in addition, new conceptive technologies have contributed to a cultural context in which procreation is now conceptualized "as subject to personal preference and choice in a way that has never before been conceivable" (Strathern 1992:34). A shift from risk-based to population-based screening has, in some areas of the United States and Europe, made every pregnant women eligible for prenatal diagnostic testing (Press and Browner 1994:201). As women undergo prenatal screening in the forms of maternal serum alphafetoprotein (AFP) testing, ultrasound, amniocentesis, or cvs, they are faced not only with imagining carrying to term an infant with disabilities, but with assessing which types of disability might be acceptable to them and which not.

What has largely been left out of the discussion of new technologies and reproduction however, has been the interpretation of "defective" children when they are actually born and as they are raised. Studies assessing the relationship of

disability and the new reproductive technologies have primarily approached disabled infants hypothetically, within the framework of pregnancy rather than of motherhood. This is ironic both in that the increase in multiple births brought about by the use of new conceptive technologies has led to increased risk of cerebral palsy (Goldstein 1996), and in that new technologies in the neonatal intensive care unit have resulted in the treatment and survival of extremely low-birth weight premature babies who in turn have been shown to be at high risk for pulmonary and central nervous system injury including cerebral palsy, mental retardation and vision impairments (Hack et al. 1994:758). Nevertheless, in society in which prenatal screening is becoming a routine part of prenatal care, most pregnant women seek and assume the possibility of having a "normal" child.

Analyzing the relationship between the feminist and disability rights movements, Hershey (1994) reminds us that fear of disability has long served as a means to garner support for abortion rights. While some women do refuse prenatal testing, the typical American pregnancy can now be characterized as "tentative" (Rothman 1986), with women being asked "to adopt the traditional male model for parenting: holding back until the child earns approval and love" (Rothman 1992:13). In the current American context then, the potential disabled child envisioned by a pregnant women is conceptualized, Press, Browner and LeMaster (1993) claim, as "the other."

However, for a women whose infant is born "damaged" or whose young child was recently labeled with a disability, the "other" is not just a hypothetical possibility, imagined but usually dismissed as an irrational fear during pregnancy. Studies carried out in the fields of psychology and counseling have long argued for understanding parental responses to an infant's disability in terms of stages of grief following the "death" of the normal child the parent had expected (see for instance Solnit and Stark 1961; Irvin, Kennell and Klaus 1976; Darling 1979; Fost 1981). Such studies tend to concentrate on determining the variables leading to successful parental adjustment to the child's disability (Drotar, et al. 1975; Singer and Powers 1993; Tunali, et al. 1993). Many studies of parents' beliefs about their child's condition tend to be judgmental - "contrasting parents' emotionally sullied, mistaken beliefs with `the truth'" (Layne 1996:643). Psychologists and service providers thus all too often describe parents' responses and behaviors in such terms as "denial," "compliance," and "acceptance of reality," and treat them as stages in a linear progression. The starting point for the study on which this article is based however, is mothers' own understanding of themselves and their children; it documents how mothers define and redefine their experience of mothering in the context of disability. The overarching question informing the research is thus not how do mothers adapt (or fail to adapt) to their child's disability, but how do they attribute meaning to their experience of giving birth to and raising a child with a disability?

Reproduction as Production

In her ground breaking work The Woman in the Body, Emily Martin (1987) analyzes metaphors of reproduction, and argues that in American culture the act of reproduction is represented as another form of production. Consistent with Martin's analysis, mothers of children with disabilities are culturally defined as the producers of defective merchandise. The widespread use of both birth control and new reproductive technologies have only exacerbated this cultural interpretation. Michaelson (1988) claims that because motherhood is now a choice rather than an obligation, women may choose to have fewer children in order to pursue other opportunities; therefore each child born must be worth it in relation to available options. At the same time, technology serves as the resource holding out the promise of the "perfect child" (Michaelson 1988:28; Ginsburg and Rapp 1991). Anthropological studies point out that while in many societies a child is understood as the embodiment of the parents' relationship with each other and with other kin, with the development of new reproductive technologies, children become the embodiment of their parents' choices (Strathern 1992:31-31). But with or without new technologies, few women actively choose a child with disabilities. Thus however appealing from the point of view of women's rights, a rhetoric of choice reveals itself as illusory to the mother of a child with disabilities, for she lives in a society that diminishes the personhood of her child and in which she herself has failed to follow the culturally approved path of motherhood.

If it is the case, as Rapp suggests, that cultural imagery is shifting toward a pregnant women as "the agent of quality control" (1988:115), then it is reasonable to ask: What is the impact of this imagery on women who bring into the world children who do not meet society's standards of quality? In this article I begin to explore the agency of mothers of children with disabilities, examining how they may accept, reject, or reconstruct cultural representations of reproduction and personhood through their own experience of mothering.

Method of Study

The data on which this article is based derive from an ongoing study of mothers of infants and toddlers identified as having a disability or as being at high risk for disability. The bulk of the mothers in the study were recruited through the Newborn Followup Program of the Children's Hospital of Albany Medical Center. This program has a 25 county catchment area encompassing rural, urban, small-town, and suburban areas. The program serves those children who spent time in the hospital's neonatal intensive care unit, as well as those who have been referred by pediatricians, daycare providers, or parents themselves. The program serves as an evaluation site for determining eligibility for early

intervention services. Since by law such services are to be provided to all eligible children without cost to the parents, the site offered the possibility to recruit a wide range of participants.

Anthropological methods of data collection and analysis were used. I carried out participant-observation at the Newborn Followup Program for over a year. Upon receiving informed consent from mothers, I observed and recorded on audiotape their child's visit to the developmental pediatrician, including the doctor's discussion with the mother regarding the child's diagnosis and prognosis. To date, 1323 developmental pediatric evaluations have been observed and recorded. Each mother who chose to continue participation in the study was interviewed in her own home or workplace. Interviews lasted from one to four hours, with data collected on the woman's age, education, religious background and current religious affiliation, marital status, work history, prenatal screening, number of pregnancies and children, and previous experience with disability. However, each interview was primarily devoted to recording the mother's story, told in her own words, of how she came to find out that her child has, or was at risk for, a disability, and her feelings about mothering a child with disabilities. Fifty-nine such interviews have been recorded on tape and transcribed.

Interviews are now being carried out one year following the initial interview. Comparison of the two narratives collected one year apart enables me to examine both the interpretations of disability and motherhood that mothers bring with them as they first encounter a diagnosis of disability, and how they may come to redefine disability, normality, and their own identity through the actual experience of mothering a child with disability.

Mothers' willingness to participate in the study may have been positively affected by reference to the researcher's own experience as the mother of a child with physical disabilities (I have a five-year old daughter with cerebral palsy). However, unlike the usual setting for what has been considered "insider anthropology," the community being studied here is one into which I and others have come late in our lives. Therefore, what we have in common is not our backgrounds. In fact, the shared community of insiders which has provided rich access to the research data is one to which few of us had expected to belong. For each member it may require a transformation of an identity that was already developed in other settings. That transformation, the development of a newly emerging identity as a mother of a child with a disability, is in part the subject of this research.

The Expectation of "Perfection"

The stories told by all women in the study indicate that they were very aware of the medical profession's advice for pregnant women, which they felt should ensure the birth of a healthy baby. Among the issues most commonly mentioned were

not smoking, not using alcohol or drugs, eating the proper foods, getting exercise, gaining "the right amount" of weight, having regular prenatal care, and taking prenatal vitamins. In reflecting on their experience of finding out about the child's disability, all women either searched for what they personally might have done wrong to bring about the disability (working too late into the pregnancy, having a drink or taking a Tylenol prior to knowing they were pregnant, etc.) or complained that they felt judged by others as having behaved improperly. Most felt it to be a profound injustice that they had in fact followed the advice of experts, and done "everything right," and yet still had a child with a disability, while other women who smoked, drank, and used drugs, or didn't get prenatal care during pregnancy nevertheless had healthy children. A mother of a child diagnosed with developmental delays and a seizure disorder reflects her sense of betrayal:

> I get angry, I did everything right to have her. Why does she have to suffer? Why do we have to suffer? We wanted her. Some people go out and have 20 million kids, and every single one of them is fine. They had six beers or whatever. It just doesn't make any sense to me. It makes you angry that you tried to do everything right.

Similarly, the mother of a child with hydrocephaly diagnosed at 16 months of age comments:

> You know, I never realized that could happen, number one. And that, why me? You ever ask yourself, why my kid? Why my kid? I never smoked. I never drank. You do, you ask yourself. I barely even ate, you know? I never did anything wrong. I had a doctor from when I was four weeks on. You think, there's no way.

A women who had earlier experienced a miscarriage gave this description of her carefully planned pregnancy and of finding out about her son's congenital heart defect:

> So I was careful not to overeat and just eat the correct foods, and take my vitamins, and I worked very hard in keeping him -- knowing he would be healthy, which he wasn't. And there's hundreds of babies that their parents eat junk food and smoke cigarettes and do drugs. These babies don't seem to be born with birth defects. The anger that you feel when you work so hard, and you still end up with a baby that's got a problem.

The narratives collected suggest that reproductive outcome is publicly presented and interpreted as subject to individual control. It is the mother, above all others, who is held responsible, first through her obligation to undergo prenatal screening and abortion of any defective fetus, and secondly, through her control of the uterine environment (Landsman 1994).

Preliminary analysis of the data suggests there are few class-based differences in how mothers respond to the labeling of their child with a disability. Elsewhere I have suggested that this is because 1) medical technologies, the availability of selective abortion of defective fetuses, and the widespread dissemination of expert knowledge about ensuring healthy pregnancies produce an illusion of control and of the potential for "perfect" babies for mothers of all socioeconomic classes who have access to and utilize the medical system; and 2) because discrimination against persons with disabilities extends broadly across class lines in American culture (Landsman 1996). In a society in which disability diminishes personhood, many mothers of children with disabilities see themselves as having entered a class by themselves; now recognizing the full personhood and humanity of their disabled child, they also have few expectations that anyone who has not experienced nurturing a child with disabilities could ever truly understand them.

However, if socioeconomic class has little relevance for women's initial interpretation of their own motherhood in the face of a child's disability, does the type of disability? Ferguson notes that even within the disability community one can "sometimes encounter an implicit pecking order of disabilities with retardation at the bottom" (1996:20). If this is so, further research is needed to assess the impact of such a culturally based "pecking order" on the experience of mothering children with developmental disabilities as compared to physical disabilities.

Motherhood, Disability, and Personhood

The issue of concern here is not how particular types of mothers do or do not adapt to having a child with disabilities, but rather how they reconstruct their concept and practice of motherhood. A mother of twins, one of whom is diagnosed with cerebral palsy, reflects on the changes she has undergone.

> I sometimes think that this occurred to make us better people. It makes me much more empathetic. I would like to think that I was pretty understanding of most people, but I think probably not. I understand more now what it's like to be a parent now and struggle, and to open up my capacity to love someone.... If there's any way to make sense out of it, which maybe there's no reason to try to do this, but if you can make sense out of it then - I think Steve would disagree and he wouldn't want to try and make sense out of it, it is what it is and this is what we deal with and there's no reason that it oc-

curred, it just is what it is - but what's come of it is it's made us better able to be understanding, not necessarily with each other (laughs). But I think, I don't even know how to explain it other than like a warmth, you know, towards other people that perhaps wasn't there, certainly towards other children who are not perfect, you know, and people who aren't perfect either....

And I always liked to pride myself on being very understanding, you know, being in the helping professions (laughs), but you just never know until you've been through something like this what it's really like to be, you know, in pain, or struggling or scared, or watch your children struggle in a way and not be able to help them.... So it's made me a lot less judgmental, a lot more understanding of struggle. It softens us, I think, which is nice. It's a good thing.

This narrative is not at all unusual in appearing to unify what on the surface appears to be contradictory emotions. (1) All mothers acknowledge that taking care of a child with disabilities is physically and emotionally exhausting. Each mother would joyfully choose to eliminate her child's disability if she could. Yet no mother expressed regret over what she had learned or over the type of person she had become because of the experience. After a long interview one women, looking out at her son with autism, commented that "it's a gift really. I wish I didn't have it, but it is a gift." Thus, as I explain in a forthcoming article:

...on the one hand, mothers speak with anger about having their enormous difficulties ignored or minimized; they speak of the agony of lost dreams, the pain of seeing other children and imagining what might have been for their own child, their fears and concerns for the future, and their frustration with a system that places unnecessary obstacles in their path and forces them to become ever more assertive. Yet at the same time, most bristle at suggestions that their lives or the lives of their children are tragic or pitiful. Most mothers I interviewed tell what at first appear to be two stories, one in which they hurt for their children and for their own losses and another in which their experience of mothering a disabled child has taught them that their children are, after all, normal and their own lives enriched. Connecting the stories is a discourse of love, often love for a child who they once might have imagined to be unlovable (Landsman, forthcoming)

Whatever transformations mothers have undergone in the early years of mothering a child with disabilities, they have largely experienced them in isolation from other mothers. The early intervention legislation's requirement that to the extent appropriate, services be provided in the child's "natural environment" has in many areas led to the provision of services almost exclusively in the child's own home. Whatever the benefits to this requirement (and there are many), as a consequence mothers of children with disabilities do not have access to the support that might emerge out of contacts made with parents in specialized, segregated center-based programs. "I can't really be the only mother of a child with CP in Voorheesville!" complained one mother in exasperation.

The mother of a toddler with cerebral palsy struggled to explain the difference in how she looks at people with disabilities since the birth of her premature baby ("I guess I look at them as human beings now, and I thought I did before") and with how to explain that sense of missed personhood to others: "And how do you get that across to other people unless -- I guess it isn't unless they're in love with a handicapped person, do you ever really sense that." This sentiment was voiced repeatedly in mothers' narratives.

My preliminary research suggests that mothers of children with disabilities are in an ongoing process of constructing their child's personhood and their own motherhood as they enter different social arenas and as they represent their child to different "audiences" - family, friends, medical personnel, child care providers, early intervention service providers, government workers, school systems, and the anonymous public, etc. Future research will seek to identify the factors that affect how mothers of children with different disabilities utilize their constructions of their child's personhood and of their own motherhood to advocate for their child in these different settings. Women who grew up in a society in which people with disabilities were segregated from the rest of society, and who thus themselves have had little prior experience with disabilities, are now the primary caretakers of young children with disabilities. (2) We must recognize that these mothers are finding their way with few role models to guide them as they advocate for their children and as they discover and proclaim, some loudly, some softly, the validity of their own motherhood and the full personhood of the child they love.

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Endnotes

1. For more extensive discussion of this point and of others raised earlier, see my forthcoming article, Reconstructing Motherhood in the Age of Perfect Babies: A Study of Mothers of Infants and Toddlers with Disabilities, to appear in the journal *Signs*.

2. This is not to suggest that fathers are not also involved in caring for their children with disabilities; research is needed to address the meanings they give to their experience.

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